

Volume 12 Issue 2

### PRESIDENT'S MESSAGE

Donna Lamping, PhD London, United Kingdom



One of the unexpected pleasures of becoming President is that I've had the opportunity to get to know so many more of you, our ISOQOL mem-

bers. I really appreciate those of you who took the time to introduce yourselves and share ideas with me at the Toronto conference, or who have sent me email suggestions about what we might do to help ISOQOL offer the most and very best for its members, and encourage those of you who have something to say to tell me, please let me know (donna.lamping@lshtm.ac.uk). I look forward to getting to know many more of you during the year ahead, and to hearing your suggestions. The newsletter is a great opportunity to keep in touch, which is why we're so grateful to Kathy Wyrwich for continuing to do such a stellar job on this!

#### Indian Summer in Toronto 07

The annual conference is a high point in the year for many ISOQOL members, but was a particularly special one for me this year as it was in my hometown! Most of us Torontonians grew up having been taught that Toronto meant "meeting place"—how appropriate to have the 2007 conference here was my first thought! but apparently that was the mistaken translation of some Victorian antiquarian. In fact, Toronto derives from an Iroquois term meaning 'where there are trees in water.' Nevertheless, those of you who

# International Society for Quality of Life Research

#### Newsletter for ISOQOL Members

made it to Toronto will have experienced first hand what we call 'Indian summer', a period of unseasonably warm weather that arrives just before we sink into the depths of Canadian winter—in this case with temperatures reaching a maximum of 87°F/30°C that week. Ah, yet another misnomer, though, thanks to Christopher Columbus' mistaken belief that he had arrived in India!!

In any case, the Toronto conference offered something for everyone, thanks to the ingenuity of our Scientific Organising Committee (Co-Chairs: Nancy Mayo and Dorcas Beaton) and the organisational wizardry of our Degnon team. We welcomed an impressive cast of plenary speakers, many of whom were welcome 'new faces' to ISOQOL this year, and introduced concurrent mini-plenary sessions at the end of each day. In response to your suggestions for more time and space to view posters and meet authors, we experimented by having posters up the entire day with two 'meet the author' sessions, as well as more but smaller posters in a larger space. Did it work for you? Tell us what you think (info@isoqol.org).

For between-session respite, there were massaging rocking chairs at the lobby waterfall garden, splendid views of the architecturally distinctive Toronto City Hall on one side and on the other the CN Tower-which just lost its 32-year distinction of being the tallest free-standing structure in the world-as well as an endless choice of multicultural culinary and other delights. For those who ventured outside the conference hotel, there were the new Libeskind, Alsop and Gehry buildings for the architectural enthusiasts, the slapshot contest at the Hockey Hall of Fame for the sports aficionados, a veritable embarrasse de richesse for the foodies and shopaholics among you and,

#### December 2007

for those who ventured farther afield, the roar of the great Niagara Falls.

Heartfelt kudos to outstanding members who were honoured at the Toronto conference: Dennis Revicki, on his well-deserved President's Award, and for letting us in on the seven things we should all know about HRQL research; David Osoba and colleagues, for their excellent paper awarded Article of the Year; and Keiko Asakawa, Fabio Efficace, Elegance TP Lam and Josefina Lugo, recipients of the New Investigator/Student awards. And, my personal thanks to everyone who made Toronto 2008 a success: the 425 conference delegates from 27 countries; the Scientific Organising Committee, so ably Co-Chaired by Nancy Mayo and Dorcas Beaton; and Laura Degnon, Sarah Shiffert and their team for making it all happen and ensuring the right balance of work and fun.

I hope to see many of you at next year's 2008 conference in Montevideo, Uruguay

President, continued on page 10

IN THIS ISSUE			
President's Message	Page 1		
Past President's			
Message	Page 2		
New Investigators SIG	Page 3		
Membership Committee	Page 3		
2007 Contributors	Page 3		
Best Article in QLR	Page 4		
<b>QLR</b> Journal Update	Page 5		
<b>Chapters Update</b>	Page 5		
<b>President's Award</b>			
Address	Page 6		
2008 ISOQOL Meeting	Page 8		
2007 Awards	Page 9		
Classified Ad	Page 11		



The ISOQOL Newsletter is published two times a year by the International Society for Quality of Life Research with the cooperation of Degnon Associates.

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## PAST PRESIDENT'S MESSAGE

By Madeleine King, PhD Sydney, Australia

> It came to be, It came at last, Your Mad President, Now President Past.

Sitting now in the comfortable chair of the Past President, I have time to reflect, with Toronto fresh in my mind. The last time I was in Toronto was 1995, en route to the 2<sup>nd</sup> annual ISOOOL conference in Montreal. I didn't know then that this was just the beginning of my wonderful journey in QOL research (a journey which I hope is far from over!). In all those years, ISOOOL has held some wonderful conferences and its members have done a lot of good work. While this has served the field well, it has not really lead to the steady growth of ISOOOL's membership that we would have liked. This has caused the Board much consternation over the years - we have puzzled over the annual membership graphs in relation to various membership initiatives and strategies, but the trends remain a mystery . . . which is frustrating, because we want to do more than just survive, we want to thrive. The good news is that this year ISOQOL has put on a sudden growth spurt - our membership is at a record all time high - 730 - a very nice thing to have happen during my presidency.

I firmly believe that ISOQOL will continue to grow through its regional chapters initiative. It has been rewarding to see the establishment this year of ISOQOL's first three chapters - the Ibero-American Chapter, the Asian-Chinese Chapter and the Russian Chapter. There are also promising developments in Singapore, Japan, Australia, Africa and Turkey, and I am confident we will see chapters in those places in the future. This is the achievement that I am most proud of during my presidency. As many of you will know, I lobbied for many years for the establishment of ISOQOL chapters beyond the traditional membership base of North America and Western Europe. My perspective and experiences as an Australian have motivated me. As anyone who has been to Australia will know, it is a long way from anywhere. So I know only too well about the geographical and financial barriers that can come between a HROOL enthusiast and an ISOOOL annual conference. I hope that the establishment of chapters, with consequent growth in HRQOL-related activities in these regions, delivers the benefits of ISOQOL around the globe and expands ISOQOL's membership both in absolute numbers and international reach. This will create a synergy that holds ISOQOL as a cohesive whole and grows ISOQOL as a diverse collective.

As with so many aspects of life, the ISOQOL leadership is cyclic - endings are met by beginnings, all part of a greater continuum. I hand over now to Donna Lamping with every confidence, and look forward to working with her, Neil, Rick, Laura, the Board and Degnon in the year ahead. I wish Donna luck, knowing she will do wonderful job.

> So look ahead, The Lamp burns bright, Now Donna's turn, To shine her light.

## 2007 INDIVIDUAL CONTRIBUTORS

Thanks to the contributions provided by the members below, ISOQOL is able to provide many programs including the funding of young investigators and investigators from underdeveloped countries to our meeting. Thank you!

Monika Bullinger, PhD Ali K. Choucair, MD Shirley Farlinger Peter Fayers, PhD Diane Fairclough, PhD Ted Ganiats, MD Paul Jones, PhD Christopher Lee, MD Takashi Mandai, MD Yoshikiyo Nagai, MD Donald Patrick, PhD Nutjaree Pratheepawanit, PharmD, PhD David Roye, MD David Gwyn Seymour, MD, FRCP Mirjam Sprangers, PhD Thad Spratlen

## RE-ACTIVATION OF THE NEW INVESTIGATORS SIG

Elsbeth F. Bloem, PhD Candidate Amsterdam, The Netherlands

Sandra Nolte, PhD Candidate Melbourne, Australia

Four years ago the Special Interest Group for New Investigators was established with the objective to create a network for investigators who are new to the field of QoL. After several successful years Sonja Boehmer unfortunately had to step down as this SIG's chair due to other commitments. We would like to thank Sonja, Albert Wu and Donna Lamping for initiating this SIG and providing a great starting point for this important special interest group.

At this year's ISOQOL conference it was decided that the work of the SIG is in need of more active engagement. It therefore gives us great pleasure to announce that the "New Investigators SIG" will be reactivated! After overwhelming encouragement and support we are hopeful that this SIG will meet the interest of those ISOQOL members who are (relatively) new to QoL research.

The "New Investigators SIG" is intended for all ISOQOL members who are full-time students, post-doctoral fellows who received their doctorate within the past 5 years, or investigators who have worked as independent researchers in the QoL field for up to 5 years.

Our ideas are to create a network for all new QoL investigators to share experiences, facilitate discussion, and help each other solve common problems at the early stages of one's career. Additionally, we would like to extend the mentor-mentee program as offered during the ISOQOL meetings into an ongoing e-mentoring program.

Our first meeting as the re-activated "New Investigators SIG" will take place at next year's ISOQOL conference in Montevideo, Uruguay. In addition to this SIG meeting we are planning to organize small events and get-togethers such as information sessions led by senior ISOQOL members on topics relevant to us new investigators. Please feel free to contact us to share your specific interests and needs!

We warmly invite you to join the "New Investigators SIG", either as a junior QoL researcher or as a senior willing to share your experiences with the "new" ones! Please send an e-mail to info@isoqol.org in order to be enrolled in the "New Investigators SIG" listserv.

We hope to see you all next year in Montevideo!

Elsbeth F. Bloem, e.f.bloem@amc.uva.nl Sandra Nolte, sandra.nolte@mh.org.au



## THE ISOQOL MEMBER-SHIP COMMITTEE NEEDS YOU! WANT TO GET MORE INVOLVED?

Joanne Greenhalgh, PhD, Chair, ISOQOL Membership Committee

If you want to get more involved in ISOQOL's activities, then joining the membership committee is a great way to do this. The membership committee is responsible for developing and implementing initiatives to retain our existing members and attract new ones. The committee, previously led by Elaine McColl, has already done some great work, including an extensive membership survey back in 2004 to find out what our members wanted. We're always looking for new ideas to meet the needs of existing members and attract new ones, especially outside North America and Europe (where most of our current members come from). We also need your help in taking the initiatives forward in as many different countries as possible. If you're interested in joining, contact Joanne Greenhalgh, the current chair of the committee, at j.greenhalgh@leeds.ac.uk.

If you don't feel up to joining the committee, there are still things you can do to help:

• If you're attending another professional meeting that shares an interest in quality of life outcomes, you could take along some brochures advertising ISOQOL. You could also put one up on your departmental notice board. Contact info@isoqol.org for an electronic file of the brochure.

• Tell your colleagues about us! Please think about your colleagues who share an interest in quality of life outcomes but who are currently not members of ISOQOL. Do you think you could interest any of them in joining us? It might help to remind them of the benefits of being an ISOQOL member, such as reduced conferences registration fees, online subscription to Quality of Life Research, discount on annual subscription to the Quality of Life Instruments Database, participation in special interest groups and the ISOQOL list serve and, of course, an opportunity to be part of an international community with enthusiasm and expertise in quality of life research. Direct them to the ISOQOL website (www.isoqol.org).



## BEST ARTICLE PUB-LISHED IN *QUALITY OF LIFE RESEARCH* IN 2006

David Feeny, PhD Portland, OR, United States

As you may know, in 2006 the ISOQOL Board voted to change the Best Article award from the best article on health-related quality of life published in the previous year to the best paper published in the Society's journal, *Quality of Life Research*, in the previous year. Editor-in-Chief Ron Hays and his team of Associate Editors were asked to review the papers that they had handled and that were published during 2006 and nominate the best for consideration for the prize. Members of the Society were also given the opportunity to nominate papers. The eleven nominated papers are listed below.

The Nominations Committee (Peter Fayers, Chair; David Feeny; Albert Wu) is responsible for making the final selection. Because Peter Fayers was a co-author of two of the nominated papers, he stepped off of the Committee to avoid any conflict of interest. Ivan Barofsky graciously volunteered to replace Peter.

The eleven papers nominated are diverse, important, and informative. Topics include models to predict depression, the effects of how interviews are introduced on subsequent responses, computer adaptive testing, health status and healthrelated quality of life in long-term followup of survivors of cancer in children, Canadian longitudinal population norms for the Short Form 36, a comparison of psychometric and clinimetric scoring for a disease-specific instrument for myocardial infarction, a synthesis of evidence on adaptation and response shift, healthrelated quality of life following cancer, and health-related quality of life associated with atrial fibrillation. The nominated papers are tangible evidence that research on health-related quality of life is alive and well.

**Papers Nominated for Best Article published in** *Quality of Life Research* in 2006 Ay-Woan P, Sarah CPY, LyInn C, Tsyr-Jang C, Ping-Chuan H. Quality of Life in Depression: Predictive Models. *Qual Life Res*. February 2006; 15 (1): 39-48.

Hopman WM, Berger C, Joseph L, Towheed T, VandenKerkhof E, Anastassiades T, Adachi JD, Ioannidis G, Brown JP, Hanley DA, Papadimitropoulos EA, CaMos Research Group. The natural progression of health-related quality of life: Results of a five-year prospective study of SF-36 scores in a normative population. *Qual Life Res.* April 2006; 15 (3): 527-536.

Jim HS, Purnell JQ, Richardson SA, Golden-Kreutz D, Andersen BL. Measuring meaning in life following cancer. *Qual Life Res.* October 2006; 15 (8): 1355-1371.

Ong L, Cribbie R, Harris L, Dorian P, Newman D, Mangat I, Nolan R, Irvine J. Psychological correlates of quality of life in atrial fibrillation. *Qual Life Res.* October 2006; 15 (8): 1323-1333.

Osoba D, Hsu M-A, Copley-Merriman C, Coombs J, Johnson FR, Hauber, B, Manjunath R, Pyles A. Stated preferences of patients with cancer for healthrelated quality-of-life (HRQOL) domains during treatment. *Qual Life Res.* March 2006; 15 (2): 273-283.

Petersen MA, Groenvold M, Aaronson N, Fayers P, Sprangers M, Bjorner JB. Multidimensional computerized adaptive testing of the EORTC QLQ-C30: basic developments and evaluations. *Qual Life Res.* April 2006;15(3):315-329.

Pogany L, Barr RD, Shaw A, Speechley KN, Barrera M, Maunsell E. Health status in survivors of cancer in childhood and adolescence. *Qual Life Res.* February 2006; 15 (1): 143-157.

Ribera A, Permanyer-Miralda G, Alonso J, Cascant P, Soriano N, Brotons C. Is psychometric scoring of the McNew Quality of Life after Myocardial Infarction questionnaire superior to the clinimetric scoring? A comparison of two approaches. *Qual Life Res*. April 2006; 15 (3): 357-365.

Schwartz CE, Bode R, Repucci N, Becker J, Sprangers MAG, Fayers PM. The clinical significance of adaptation *Qual Life Res.* November 2006 15 (9): 1533-1550.

Schwartz C, Welch G, Santiago-Kelley P, Bode R, Sun X. Computerized adaptive testing of diabetes impact: a feasibility study of Hispanics and non-Hispanics in an active clinic population. *Qual Life Res.* November 2006;15(9): 1503-1518.

Smith DM, Schwarz N, Roberts TR, Ubel PA. Why are you calling me? How study introductions change response patterns. *Qual Life Res.* May 2006; 15 (4): 621-630.

#### And the Winner Is....

The committee is delighted to report on its unanimous choice for the best paper published in *Quality of Life Research* in 2006.

Osoba D, Hsu M-A, Copley-Merriman C, Coombs J, Johnson FR, Hauber, B, Manjunath R, Pyles A. Stated preferences of patients with cancer for healthrelated quality-of-life (HRQOL) domains during treatment. *Qual Life Res.* March 2006; 15 (2): 273-283.

In the paper the authors explore the association between the importance that patients attached to various domains of health-related quality of life and domains affected by their disease and/or stage of treatment. Three hundred eight-four patients completed the EORTC QLQ-C30 and provided responses to a stated preferences questionnaire about the importance of various domains and symptoms included in the EORTC questionnaire. Physical functioning was rated as the most important domain, followed by social and role functioning, pain, and fatigue. There were some associations between the type of cancer and the relative weights to domains on the QLQ C-30. The authors concluded that "the symptoms resulting from the kind and stage of disease and treatment are a strong determinant of the effects that patients most wished to avoid" (p. 282). The stated preference approach revealed important information about what is important to patients.

Congratulations to all of the authors of the papers nominated. As you read papers published in *Quality of Life Research* in 2007, please consider nominating papers that really impress you for the prize next year.



## *QUALITY OF LIFE RESEARCH* JOURNAL SUMMARY FOR FIRST 9 MONTHS OF 2007

Ron D. Hays, PhD, Editor-in-Chief Los Angeles, CA USA

Manuscript Flow and Decisions. A total of 415 manuscripts were submitted between January 1, 2007 and September 30, 2007 (approximately 341 manuscripts were submitted in 2006 over the same time interval; estimate based on total of 493 submissions during all of 2006). The 415 manuscripts included 249 that were rejected, 23 accepted, 60 that are under revision, and 83 that are undergoing peer review. The estimated acceptance rate is approximately 24%. The estimated acceptance rate was 27% in 2006, 32% in 2005, and 40% in 2004. We have a total of 1800 pages budgeted for 2007 (plus the supplement). In 2006 the page count was about 1540. Previous years page totals were 2358 in 2005, 1782 in 2004, and 1148 (plus 94 page supplement) in 2003.

Excluding the manuscripts rejected without review, the average time between submission and initial decision in 2007 was 63 days (range: 23-219).

Publication is on schedule, with online publication of Volume 16 #'s 1-9 (February, March, April, May, June, August, September, October, November).

The impact factor for *Quality of Life Re*search in 2006 was 2.037 (compared to 1.915 in 2005 and 1.820 in 2004), with a ranking of 15<sup>th</sup> out of 56 in the "health care sciences and services" category (33 out of 98 journals in "public, environment and occupational health" category).

**Supplement**. Bryce Reeve, Chi-Hung Chang, and Ron Hays co-edited a special issue of the journal that includes 16 papers from the June 2004 IRT meeting sponsored by the National Cancer Institute (NCI) and the Drug Information Association (DIA), "Advances in Health Outcomes Measurement: Exploring the Current State and the Future of Item Response Theory, Item Banks, and Computer-Adaptive Testing." This special issue was published in the summer. Tenure of Associate Editors. There are 13 active Associate Editors: Carla Bann, John Brazier, Chih-Hung Chang, Jason Cole, Marie-Louise Essink-Bot, Cynthia Gross, Graeme Hawthorne, Elaine McColl, Carol Moinpour, Luis Rajmil, Michael Ritsner, Carolyn Schwartz, and Henrica de Vet. Five Associate Editors retired last year (Diane Fairclough, David Feeny, Jeanne Landgraf, Kathy Lohr, and Albert Wu) and Carolyn Schwarz is rotating off this year.

**Best Reviewers**. At the end of this year we will be identifying the outstanding reviewers for 2007 (individuals who have reviewed at least 3 times and their reviews been rated highly by the handling editors) in the ISOQOL newsletter and sending them a letter of acknowledgement. In addition, Springer will offer these reviewers a choice of a one-year subscription to *Health Services & Outcomes Research Methodology* (published 4 times/year) or the 2007 Regional Zagat Guide.

Our reviewer participation rate (agreement to review a manuscript when asked) among potential reviewers was 36% in 2006 and is 33% so far in 2007. The journal depends on timely and high quality reviews to function effectively. We are hopeful that the participation rate will improve to ensure the success of *Quality of Life Research* in the future.



### CHAPTERS UPDATE

John Brazier, Board Chapter Liaison, United Kingdom

Madeleine King, Australia

Cynthia Gross, United States

We are delighted to say that 3 chapters have been formally approved by the ISOQOL Board. These chapters are the Ibero-American (led by Juan Dapueto and Laura Scharwartzmann), Asian Chinese (led by Kwok-Fai Leung), and Russian (led by Tatyana Ionova and Andrei Novik). We are looking forward to at least two more final applications, one from Japan and the other from Singapore. We also expect some other expressions of interest to be developed into full proposals in due course.

This is a major new and exciting initiative for ISOQOL. It helps to promote one of the key goals of ISOQOL that of promoting quality of life research around the world. Local chapters will help achieve these goals in a number of ways. It means that the society will be able to improve access to ISOQOL activities by making them more local (and so reducing air miles and cost). The activities of these chapters will be more focused on local issue and needs of society members. Finally, it will be a chance for clinicians, researchers and policymakers with an interest in quality of life research to find out more about the Society. Overall we anticipate it will substantially increase membership over the coming years.

We strongly encourage further applications at any time. The website contains the current the Guidelines for Chapters on National and International Chapters of ISOQOL. We do, however, ask that you send us an expression of interest initially, so that we can help you in the process.



## 2007 PRESIDENT'S AWARD ADDRESS

The Closing Ceremonies of the 14<sup>th</sup> Annual Meeting in Toronto were held in the impressive Hockey Hall of Fame. At this fun event, outgoing President Madeleine King presented ISOQOL's President Award to the very deserving Dennis Revicki! As the 2007 Award recipient, Dennis shared his knowledge and warmth with all of us during the morning's plenary session, which is summarized in this following article.



#### SEVEN INTERESTING THINGS I'VE LEARNED ABOUT HEALTH OUT-COMES RESEARCH

#### Dennis A. Revicki, PhD Bethesda, MD USA

Although I have learned many things about health outcomes research over the past 25 years, in the interest of time I thought that limiting my commentary to just seven seemed reasonable. Further, discussions with my colleagues Peter Fayers, Paul Kind and others indicated that seven seemed a mystical number (see seven pillars of wisdom; dance of the seven veils, etc.). Therefore, I'll limit my remarks to only (1) the primacy of the patient's perspective; (2) definitions and conceptual issues; (3) measurement error and bias; (4) qualitative versus quantitative research; (5) mysteries of responsiveness and minimal important differences (MID); (6) modern measurement theory and future of health-related quality of life (HRQL) assessment; and (7) impact of other cultures on understanding HRQL.

I and other health outcomes researchers believe that the patient's views and per-

spective are key to understanding impact of disease and treatment on HRQL and other outcomes. However, often it is necessary to interpret and synthesize the patient's perspective when examining qualitative data derived from focus groups, individual interviews and cognitive debriefing studies. There is an apparent danger in allowing researchers, clinicians, and regulators to introduce their own perspectives in translating the patient's voice. Ethnographic researchers know that it is almost impossible to avoid biasing interpretations of different cultures and work toward minimizing there viewpoints when studying other cultures. When developing new health outcome instruments, there is an interaction between the instrument developer perspective and the analysis of patient-based qualitative data. Who decides and interprets the patient's perspective? We need to ensure that instrument developers, clinicians and regulators avoid introducing their interpretation and bias in reflecting the patient's viewpoint in instrument development and the evaluation of content validity.

Over the past 30 years or so, there has been a lot of varied and use for definitions and concepts in health outcomes research, and quality of life has been defined using a remarkable range of constructs and measures (Bergner 1989). The history of health outcomes research contains varied definition and conceptual issues, and we have seen the evolution of terms from health status to quality of life to HRQL to now the commonly used rubric of patient-reported outcomes. However, as health researchers we need to pay attention to our conceptualizations and we need to be clear about what is being measured and how it is being measured. I encourage the increased use of clear and meaningful labels for health outcome instruments based on clear conceptual frameworks (content maps).

We need to learn to live with measurement error and bias. All human measurement contains some error and bias. However, we need to focus our attention on the systematic and careful development of health outcomes instruments aimed at reducing sources of measurement error. Certainly psychometric analysis can help us understand source of error and direction of bias. Research on recall bias for pain and fatigue assessments by Arthur Stone and colleagues have demonstrated some differences between pain and fatigue intensity ratings between daily momentary assessments and 3, 7 and 28 day recall, although there are substantial correlations among all measurements (Stone, personal communication, September 2007). However, it is largely unknown whether this recall bias would significantly impact comparisons among treatments. The good news is that, generally, measurement error makes it more difficult to detect effectiveness in a health care intervention.

I sometimes observe a tension between qualitative and quantitative research in health outcomes. Qualitative research is very useful for generating information and hypotheses about health constructs. For instrument development, focus groups and interviews assist in identifying relevant domains and facets within domains, and provides information basis for the conceptual framework of health outcomes instruments. Qualitative studies define content and inform instrument development (no garbage in), while quantitative research confirms that the instrument content and items are reliable and valid (no garbage out). As Peter Fayers aptly noted during an ISOQOL presentation in 2006, psychometric analyses really only evaluate whether we did a good job in instrument development (Favers 2006). Qualitative and quantitative research methods are interlocked and provide complimentary evidence on the measurement quality of instruments. Qualitative studies may be viewed as exploratory while quantitative studies may be viewed as confirmatory. Note that there may be subjective bias in design and conduct of both types of studies. We need to be careful about researcher bias in analysis and interpretation of information. Anthropologic studies suggest everyone has a biased prospective and that we need to understand and recognize sources of bias and try to minimize these influences.

Is there really continued mystery sur-

rounding the evaluation of responsiveness and MID? The recommended approach, and evolving consensus involves estimating the MID based on several anchor-based methods, with relevant clinical or patient-based indicators. These anchors need to be correlated with the target health outcomes measure and relevant for the disease and patient population. For example, Farrar et al. (2001) examined the clinical significance of changes in pain intensity ratings based on global ratings of change and examined the sensitivity and specificity of various criteria for meaningful changes. Various distribution-based estimates (i.e., effect size, standardized response mean, etc.) may then be reviewed as supportive information. Next it is important to triangulate on a single value or small range of values for the MID. Confidence in a specific MID value evolves over time and is confirmed by additional research evidence, including clinical trial experience (Revicki et al. 2007).

Increasingly, modern measurement theory based methods are being used in the development and psychometric evaluation of health outcome measures (Reeve et al. 2007). Item response theory (IRT) analysis and classical psychometric analysis compliment and contribute to understanding item performance and the structure of health outcome measures. IRT methods allow scaling of people and items on same metric and estimation of measurement error along the health domain continuum. These approaches enables informed selection of short forms and computer adaptive testing (individualized assessment) in health research and potentially the development of more responsive health outcome measures. For example, Revicki et al. (2005) examined the responsiveness of three IRT based depression severity measures developed based on standard depression severity measures (Table 1). Based on this research, the IRT based depression severity measures were as or more responsive that the Hamilton Depression Rating Scale or the Montgomery-Asberg Depression rating Scale. The investigators participating in the NIH PROMIS initiative are developing item banks to measure physical function, pain, fatigue, social activities, emotional disTable 1: Treatment Comparisons and Effect Size Estimates for Baseline to Endpoint Changes in Depression Severity Scale fro Paroxetine and Placebo Groups

Score	Paroxetine Least Square	Placebo Mean Change	P-Value	Effect Size
HDRS total	-11.4	-8.4	0.007	0.43
MDRS total	-13.6	-8.8	0.001	0.54
DS-1 score*	-17.3	-12.1	0.004	0.46
DS-2 score*	-21.9	-13.7	0.0002	0.59
DS-3 score*	-23.1	-14.2	0.0001	0.63

 $\ast$  IRT based depression severity scores derived from HDRS and MDRS items; T-scores with mean of 50 and SD of 10

Abbreviations: HDRS = Hamilton Depression Rating Scale; MADRS += Montgomery-Asberg Depression Rating Scale; DS = depression severity

tress and other domains (www.nihpromis.org), and these measures may help advance outcomes assessment.

Finally, I have become increasingly aware about the impact of other cultures on understanding HRQL measurement. To date, there has been a predominant Western influence on HRQL instrument development and this perspective results in a particular conceptual and domain structure. People around the world value good physical functioning, psychological wellbeing, and social well-being and generally the ability to live their lives, but other domains are more important in Eastern cultures. The challenge is in developing health outcome instruments for international clinical trials. For example, in India, piece of mind, spiritual satisfaction, happiness with family, and fulfillment of basic needs are important for quality of life (Chaturvedi 1991). We, as health outcomes researchers, need to ensure that new health outcome measures are translatable and are culturally relevant in countries around the world.

In conclusion, the patient's perspective and patient-reported HRQL is the ultimate outcome for health care interventions. There is a real need for the continued development and application of culturally relevant and psychometrically sound health outcome instruments. The future focus on item banks, computer adaptive testing and other advanced psychometric methods in HRQL research may help us advance health outcome assessment. For clinical trials, we need to focus on statistical analysis methods for handling missing and longitudinal HRQL data. We can always improve out research methods and measures, and this continued evolution is critical in advancing the field of HRQL research.

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Fayers P. President's address. Annual meeting of the International Society for Quality of Life Research, Lisbon, Portugal, October 2006.

Reeve BB, Hays RD, Bjorner JB, Cook KF, Crane PK, Teresi JA, Thissen D, Revicki DA, Weiss DJ, Hambleton RK, Honghu

President's Award, continued on page 11

### MARK YOUR CALENDAR . . . ISOQOL 2008 ANNUAL SCIENTIFIC MEETING

The next ISOOOL Conference will take place in South America for the first time. The place: MONTEVIDEO, URUGUAY. The dates: October 22 to 25, 2008. Many of you will possibly wonder where is that? What am I going to find if I go down there? Is it safe? How could someone possibly have the idea to go to this unknown place? These were some of the questions next year's chairs, Laura Schwartzmann, MD and Juan Dapueto MD, tried to answer through the presentation of Uruguay's General Consul in Toronto, Mr. Fernando López Fabregat and a DVD presentation that allowed us to know the country and its music so well, that we almost finished dancing "tango" at the session.

#### WHERE IS URUGUAY?

Uruguay is a small country located in the southeastern part of South America. It is home to 3.3 million people, of whom 1.7 million live in Montevideo, the capital and its metropolitan area. It is bordered by Brazil to the north and Argentina to the west and opens freely to the sea in the South and Eastern Coast. This ideal location makes it a perfect venue for Conferences since you can fly directly to Uruguay or take advantage of the location for pre or post Congress tours to Buenos Aires, Argentina or Rio de Janeiro in Brazil, a very short flight will also take you to the amazing Iguazu Falls or to the hidden city of Machu Pichu in Peru, through recently incorporated flights to Lima, Peru. The majestic Andes and Santiago de Chile can also be reached in a couple hour flights. So, mark your calendars ahead of time and plan a nice vacation with very good weather!!!

#### WHAT WILLI FIND IN MONTEVIDEO?

The Conference will be held in Montevideo, at the Radisson Victoria Hotel, in front of Independence Square in downtown area, very close to the charming Old City. You can stroll along the streets any time and you will feel perfectly safe. Shopping, good food, lots of meat (also vegetarian menus, don't be afraid!!) at very convenient prices, cultural activities or a tango lesson will be perfectly available within a few blocks<sub>ii</sub> If you go for good food, you can savor cuisine with traditions of different origins, from the classical grilled beef ("parrillada"), world renowned for its particular flavor and excellent quality, to characteristic dishes of the Spanish or Italian cuisine, and a wide variety of pasta and sea food. There is a great variety when it comes to restaurants.

If you like to wander around, you will find a city founded by the Spanish in the early 18th century, still keeping a Europen flavour. Most Uruguayans (88%) are of European descent, mainly Spanish and Italian, with no detriment of other nationalities, the result of an "open doors" migratory policy. Uruguayans are known for being good hosts, hospitable and solidary and always attentive to rendering a service to the visitor.

Transportation within Montevideo is very easy and most interesting places are at walking distance. Even the airport is only a 15 minute ride in a taxi that will leave you in the heart of the city, going through the "Rambla", montevideans' favourite place, alongside the sea-shore. If you are the "cultured-bias" visitor, Montevideo can offer Uruguayan culture through multiple artistic expressions. Among its world renowned painters, there stand out: Blanes, Barradas, Figari, Torres García, Cúneo and Solari. Music has its best representatives in the styles of "candombe", "murga" and "tango". And while Argentinians will greatly oppose, we can tell you that the greatest tango interpreter, Carlos Gardel, "The Magician", was native of this country.

## IS IT A DEMOCRATIC "FRIENDLY" COUNTRY?

Uruguay is politically organized as a democratic and representative republic under a presidential system. Since the first Constitution of the Republic (1830), the Legislative, Judicial and Executive powers are independent. Uruguay has a wide variety of landscapes, keeps a perfect balance, stable weather all year-round, green prairies, refreshing beaches and exceptional care of the environment. Uruguay is a privileged zone of the world due to its low degrees of environmental pollution and its unusual preservation of nature. Human capital is also outstanding, with a literacy rate of 97% and a large urban middle class, which make it a very friendly spot for visitors.

## WHY CHOOSE URUGUAY FOR ISOQOL 2008

Ten reasons for choosing Uruguay



**SECURITY**: Uruguay is one of the safest countries in the world. Offer peace of mind to your convention guests and to the meeting itself, in any city,

at any time.

**INFRASTRUCTURE**: Uruguay offers easy access from any part of the world, adequate domestic communications, well-

equipped halls, quality hotels, state of the art equipment and professional organisers.



**NOVELTY**: Uruguay is a place where you can enjoy nature any time of the year. Distances are short and it is possible to



organise a visit to the beach, one or more daystays at an "estancia", or a game of golf only a few minutes away from our hotel.

**HISTORY**: Uruguay is a bridge between American and European history. Once part of the Spanish Empire, it holds many testimonies of the Colonial past. Yet it also

keeps the memory of its aboriginal population and of the multiple migrations that have left their trace on its people and culture.



#### **ENTERTAINMENT:**

Music of all kinds: tango, folklore, "candombe", and all other international



variations of music. There are concerts permanently, which include the visit of well-known international musicians. Discos and casinos in all the big cities and an infinite number of bars where you can have a drink at any hour.

**CORDIALITY**: Uruguayans are good hosts and friendly by nature. Whether from the country or the city, they are always ready to help the visitor and enjoy



a friendly chat, to exchange opinions and experiences with other people.

**CLIMATE**: There are no extreme temperatures in Uruguay. The average is 12°C in

winter and 25°C in summer. The sky is clear and there is no level of contamination in the air.



**CULTURE**: Uruguay has the highest literacy rate in the continent - 97% - and the majority of the population has completed secondary, technological or university studies. There is a rich tradition of writeraction writeraction witeraction writeraction witeraction witeraction writeraction wri



ers, artists, musicians and scientists, many are or have been distinguished international figures. Museums, exhibitions and cultural centres can

be found in any of the Uruguayan cities. The country occupies the sixth position in the Environmental Sustainability World Index 2002.

GASTRONOMY: The national dishes include traditions of very different ori-

gins. From the classical "parrilla" - typical speciality of beef and other of its sub-products, roasted over coals - to the characteristic Spanish or Ital-



ian dishes. The Uruguayan menu is tasty and varied, and its wines have gained international recognition. Many other national dishes, which have arrived in the country with different immigration waves, can also be tasted.



FUTURE: The level of education of its inhabitants and the investments made in strategic areas, produce a favourable forecast for the country's next decade. As key access to Mercosur, a market of 200 million inhabitants, it is also a primary strategic enclave. Plan your convention in a country with a growing future. For additional information visit www.turismo.gub.uy www.uruwashi.org http://www.alluruguay.co



## STUDENT AND NEW INVESTIGATOR AWARDS -- 2007

Carolyn Gotay, PhD Chair, ISOQOL Education Committee Honolulu, HI, USA

One of the highlights of the ISOQOL annual conference is the participation of students and new investigators in early stages of their careers. Meeting these developing researchers and talking to them about their work is inspiring, informative, and fun. ISOQOL honors students and new investigators with particularly distinguished meeting posters and oral presentations. This year, the nominees represented four continents. They are listed below in each category, along with the number of the nominated abstract and their countries of residence:

#### **Student Poster Finalists**

Jeanne T. Black, 1333, USA Elegance T. P. Lam, 1472, China Matthew Kowgier, 1593, Canada

**New Investigator Poster Finalists** Josefina Lugo, 1569, Cuba Ida Korfage, 1173, Netherlands

#### **Student Oral Presentation Finalists**

Keiko Asakawa, 1283, Canada Eduardo Chamochovich, 1553, Brazil Sukyung Chung, 1791, USA

## New Investigator Oral Presentation Finalists

Fabio Efficace, 1263, Italy Walter Wodchis, 1733, Canada

A panel of more than 20 distinguished judges participated in evaluating the presentations at the meeting, attending the poster and paper sessions and asking questions of the presenters. Their ratings determined the winners, who were **Elegance T. P. Lam, Josefina Lugo, Keiko Asakawa,** and **Fabio Efficace**. Congratulations to all of these outstanding junior scientists and many others who made outstanding contributions to the ISOQOL meeting. You're off to a great start, and we look forward to learning about your continued excellent work!

#### President, from page 1

from 22-25 October, as it promises to be a very special event. Not only will it mark the 15<sup>th</sup> anniversary of ISOQOL, but this will be our first annual conference in Latin America. So, have a think about what exciting new work and/or ideas you can share with us in Montevideo, and start practicing your tango and gearing up for parrillada, beaches and gauchos!

#### The Society: What's New? Membership: An all time high

Not only have we grown substantially in a relatively short period (an over 60% increase in membership since 1999), but our membership has reached an all time high at 739 members! The more we grow, the more we are able to offer our members, so why not think about encouraging someone you know and who might benefit to join ISOQOL this year?

#### **National and Regional Chapters**

Thanks to Madeleine King's spearheading efforts and support from John Brazier, we are delighted to welcome our first three new Chapters-the Ibero-American Chapter, the Asian Chinese Chapter, and the Russia Chapter. Proposals from other groups to form chapters are in progress, and we look forward to continued growth in this area. This exciting new venture to form national and regional chapters will allow us to reach beyond ISOQOL's traditional base. If you and a 'critical mass' of colleagues in Asia, Latin America, Eastern Europe, Africa, Australia, New Zealand, or any other country outside North America and Western Europe, are interested in helping bring the benefits ISOQOL has to offer to your country or region, please see the guidelines about how to establish a chapter to the ISOQOL website (http://www.isoqol.org).

#### **Fundraising Initiative**

We are also busy at work on a new fundraising initiative, having engaged Capital Development Strategies, a Washington area based firm that specialises in non-profit organisations. We are in the early stages of this new initiative, so watch this space. Huge credit to Rick Berzon and Laura Degnon for their ongoing commitment over many years to get this off the ground and up and running and getting the ISOQOL leadership fully on board and excited about this new venture!

## Quality of Life Research: Kudos to the Society's Journal

We are delighted to hear from Ron Hays (Editor, QOLR) that: i) the journal's impact factor increased to 2.037 in 2006 (from 1.915 in 2005 and 1.820 in 2004), with a ranking of 15<sup>th</sup> out of 56 in the "health care sciences and services" category; and ii) there are plans to start a brief paper series this year, with 1-2 published pages devoted to survey or methods/statistics issues such as power calculation, estimating responsiveness to change, reliability, etc. It is thanks to the tremendous commitment of Ron and the Editorial Board that ISOQOL has such a flourishing journal of which we are so proud.

#### **Building for the Future**

Now that we are approaching the 15th anniversary of ISOQOL, we have reached a stage in our development at which I believe the collective memory and wisdom of our past leaders would be a tremendous asset in deliberations about the future growth and development of our Society. We are therefore looking at ways to involve Past Presidents of ISOQOL in the Society's strategic planning efforts. At the other end of our membership spectrum, we are also looking for ways to enhance the involvement of new investigators, who we look to for fresh, new ideas in future planning and many of whom we hope will be tomorrow's rising stars and contribute to Society leadership in future. I am particularly delighted that Elsbeth Bloem and Sanda Nolte have stepped forward to take over the reins of our New Investigator Special Interest Group (SIG), and would like to extend a very warm thanks to both, as well as to Sonja Boehmer who initiated and successfully chaired this SIG over many years. To promote the development and growth of SIGs, we have appointed a Task Force (Lena Ring, Cindy Gross, Laura Degnon) to look into ways of facilitating Board support to SIGs.

## Board of Directors: New Faces and Fond Farewells

Finally, the Board of Directors extends a warm welcome to its new members-Neil Aaronson (President-Elect), Juan Jose Dapueto and Monserrat Ferrer, as well as our huge thanks to retiring members-Peter Fayers (Past President), Elaine McColl and Graeme Hawthorne. We will all miss Madeleine King's brilliant leadership over the past year, not to mention that special Aussie wit and flair, which has brought such a welcome breath of fresh air in moments of intense deliberations and an undeniable charisma to all of the Society's activities. But, she is not off the hook yet as she continues to play an active and vibrant leadership role as Immediate Past President on the 2007-08 Executive Committee. If you've always wondered who some of these folks are, and know their names but not their faces, I'm pleased to say that we now have photos on the ISOQOL website to help you put faces to names (see Leadership Structure).

With best wishes for 2008, and hoping to see many of you in Montevideo and/or hear from some of you before then!



#### CLASSIFIED AD

#### Cancer Australia Chair in Cancer Quality of Life

Reference number: S07/026

We are seeking an outstanding individual to contribute to improve the quality of life for all those who are impacted by cancer and its treatment. The Psycho-oncology Co-operative Research Group under the auspices of the University of Sydney is pleased to offer the Cancer Australia Chair in Cancer Quality of Life.

The successful candidate will have: a PhD in psychology, public health, or relevant health related discipline with an international reputation and a distinguished record of scholarship, research, publication and research in Quality of Life; demonstrated ability to effectively build and manage an active research program and attract research funding; a record of excellence in teaching and research training; demonstrated capacity for effective academic leadership; excellent management skills, including a willingness and ability to perform high-level administrative tasks; demonstrated ability to participate and provide leadership in working with universities, government agencies, health and medical bodies and professionals, health consumers and the wider community.

The position is available on a full-time 3 year fixed term basis, and is subject to the completion of a satisfactory probation period for new appointees, and continuing funding from Cancer Australia. Membership of a University-approved superannuation scheme is a condition of appointment for new appointees.

Specific inquiries concerning the position should be directed to Prof Phyllis Butow, Professor of Psychology: +61 2 9351 2859 or email phyllisb@psych.usyd.edu.au.

For a full information pack, including details of selection criteria and how to apply, please contact Kevin Mitchell, Senior Recruitment Manager: Tel: +61 2 9979 4409 or k.mitchell@usyd.edu.au.

Closing date:15th Jan 2008



#### President's Award, from page 7

L, Gershon R, Reise SP, Lai J, Cella D. Psychometric evaluation and calibration of health-related quality of life items banks: plans for the patient-reported outcome measurement information system (PROMIS). *Med Care*. 2007;45 (5 Suppl 1): S22-31.

Revicki DA, Chen W, Frank L, Morlock R. Development and analysis of item response theory based short form Hamilton Depression Rating Scale. International Society for Quality of Life Research, San Francisco, CA, October 2005.

Revicki DA, Hays RD, Cella D, Sloan J. Recommended methods for determining responsiveness and minimally important differences for patient-reported outcomes. *J Clin Epidemiol* 2007 (electronic advance of publication).



### 2007 INSTITUTIONAL MEMBERS

ISOQOL would like to thank the following 2007 Institutional Members:

**Corporate Member** Eli Lilly

#### **Institutional Members**

RTI Health Solutions QualityMetric, Inc

#### **Non-Profit Institutional Members**

CHERE (Center for Health Economics Research and Evaluation) CORE (Center for Outcomes, Research and Education) NCI (National Cancer Institute) University of Sydney



## ADVERTISING RATES

ISOQOL Members:

1st 10 lines - no charge 11 or more lines - \$10/line

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Each line contains approximately 36 characters and spaces; this figure is an estimate only; advertisers will be charged based on the actual number of lines printed in the newsletter. If you have any questions, or if you wish to advertise a position opening, please contact the ISOQOL Executive Office.

## Mark your Calendar. . .

## ISOQOL 15th Annual Conference October 22 - 25, 2008 Montevideo, Uruguay

Visit www.ISOQOL.org for the latest information.

## Now Available online at www.isoqol.org!

Slides from the ISOQOL Conference on Patient Reported Outcomes in Clinical Practice held June 24-26, 2007 in Budapest, Hungary

## ISOQOL MEMBERSHIP BENEFITS

Know someone who might benefit from ISOQOL membership? Share these benefits with them and encourage them to join today!

- ✤ Online Membership Directory
- \* Online access to *Quality of Life Research* Journal at no additional charge!
- \* Reduced subscription rate for paper copy the Quality of Life Research Journal
- \* Participation in a variety of Special Interest Groups
- ✤ Reduced conference registration rates
- \* Opportunity to present and hear cutting edge research presentations and posters
- \* Opportunity to have special interest group meetings at the annual meeting
- \* Access to the "Members Only" section of the ISOQOL website an invaluable resource tool!
- ✤ Participation in a variety of committees
- \* Participation in the ISOQOL listservs email communication with other QOL experts
- \* Exposure to and participation with other professionals involved in quality of life research activities
- Discount on annual subscriptions to the Quality of Life Instruments Database, offered by MAPI Research Institute
- ✤ Complimentary receipt of newsletters
- While supplies last: Quality Metric's 9-CD set "Understanding Health Outcomes: An Accredited Educational Series on CD-ROM. Series One: Health Status: Concepts, Measures, and Applications"

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